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ABSTRACT

Designed for parents of handicapped children in Kentucky, the booklet contains suggestions for parent involvement and advocacy. Planning informal activities is the focus of the first section which covers informal get togethers, discussion groups, and film viewing sessions. Planning steps for more formal group activities such as workshops are considered in the second section, which addresses questions of parent needs and child care. A primer on publicity summarizes newspaper, television, and radio coverage as well as the use of newsletters. The final section reviews the functions of the State Advisory Panel for Exceptional Children, the Developmental Disabilities State Planning Council, and the Committee for a Comprehensive System of Personnel Development. (CL)

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A PARENT'S GUIDE

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Kentucky Department Of Education
Bureau of Education
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Kentucky Department of Education
Bureau of Education for Exceptional Children
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Contents

	Page
Introduction	1
Informal Activities	5
Formal Group Activities	9
Activities Summary	14
A Primer on Publicity	15
Advisory Groups	20

INTRODUCTION

New legislation guaranteeing full services to children with special needs has made both parents and professionals aware of their roles and responsibilities in providing these children appropriate educational opportunities.

Recognizing its responsibilities, the Bureau of Education for Exceptional Children has made a special commitment to parents - to interpret the new laws, to work toward increased communication among agencies providing services, to coordinate services available to insure effective education, to inform parents of their rights and those of their children, and to provide parents with increased skills and knowledge for working with their handicapped children.

It is the belief of the Bureau that parents in partnership with the local school system is the most positive step towards insuring successful, appropriate educational programs. To assist the two groups in planning for common goals, this booklet outlines ways in which parents can (1) become involved with other parents of handicapped children, (2) work with local school personnel to inform others in the community of the needs of these children, and (3) maintain an ongoing system for keeping aware of new trends, developments and information on programs and serve as a source of ideas for initiating parent involvement sessions. With the creativity and interest of dedicated parents, many exciting learning experiences can be provided.

PURPOSE

This booklet is designed for you, A PARENT, to be used as a guide for planning parent-to-parent activities in your community.

As an advocate for handicapped children, you have many challenges. Two of the greatest are organization of community support and organization of a support system for families of handicapped children.

As the parent of a child with special needs, you have an opportunity to serve as a leader in effecting change with

other parents
community agencies
public schools
local governing boards
the legislature
local, state and federal leaders

This booklet can serve as a checklist for details, as a generator of ideas, as a source of support to which you bring your unique creativity, resources, needs, and desires. To the checklists provided in this manual, you can add commitment, enthusiasm and energy, because

it's worth it.
it's a good way to change things.
it's needed--and no one knows that better than you!

INVOLVEMENT

Recently more and more educators have realized that the involvement of parents is crucial to the success of programs for children with special needs. Parents can provide a number of services which are extremely beneficial to these programs. They can serve as aides in the classroom, volunteers, members of boards and councils dealing with the concerns of handicapped children and, most importantly, as effective, patient and loving teachers in the home.

In a broader sense, parents can actually determine programs made available to children with special needs. By becoming involved in the legislative, administrative and program development process and by effectively advocating the right of all children to education, parents have been a major factor in the creation of many of the programs available today. Obviously, parent involvement is important.

The organization of any activity requires hard work; it will keep you on the telephone, at the typewriter and talking with people. However, anyone can do it ... it does not require the skills of a professional.

As the parent of a child with special needs, don't wait for school personnel, newspapers, other parents, legislators, your school board, etc., to come to you! GO TO THEM! ASK QUESTIONS! PROVIDE SUGGESTIONS AND INFORMATION!

OUTLINE

There are four major sections within this booklet. The first contains suggestions for planning different types of Informal Activities.

The second provides tips for Organizing and Conducting Group Activities such as a workshop. At the end of the second section there are three areas which are of a general nature and applicable to any activity, topic or format. These are: Needs Assessment Survey; Child Care; and Nitty-Gritty Questions.

The third is a Primer on Publicity. Several types of publicity are discussed with important considerations for each.

The fourth section describes state-level Advisory Groups that seek direction and advice from the public.

You may also seek additional resources and assistance from your school district and the Bureau of Education for Exceptional Children.

INFORMAL ACTIVITIES

Presentations

One type of activity could take the form of presentations to: town board, school board, civic organizations, legislators, university/college faculty or students.

YOU have important information to share. YOU have important information about your child and about children with special needs in general which the community may not have.

In order to provide acceptance and service, the community requires awareness and understanding. Any and all of the above groups would be interested in knowing the special needs of your child and you. For instance, the need for:

* finding money to pay for special medical care.
* finding babysitters
* finding appropriate places for and types of recreational or play experiences.
* finding preschool or school programs.

These same groups would be interested in knowing all the ways your special child is like all children: the ways your child grows, learns, loves, lives, plays; and the things which are important to your child: parents, brothers and sisters, grandparents, neighborhood, home, church, school.

Steps in Making a Presentation:

1. Form a Parents' Committee for the purpose of designing a presentation.
2. Contact the head of the target organization.
3. Contact the program chairman of the organization.
4. Receive a date for the presentation.
5. Plan the presentation.
6. Deliver the presentation.

An Informal Get-Together

An excellent way to meet and talk with teachers, administrators, child development specialists and therapists, is to have an informal party. Simple refreshments, such as coffee and doughnuts or soft drinks and chips, provide an atmosphere which encourages conversation. Many persons who are not ready to ask questions or make comments during a meeting or conference will find the informal get-together a time during which they can ask questions, make suggestions, talk and listen.

A party such as this requires planning. Two or three parents might volunteer or be asked to give the party with you. Don't hesitate to ask a parent whom you have never met to participate. Most people enjoy a party and the parent will probably be pleased to have been included in the planning.

First, decide on a date and time. Since you want professionals and parents to come together, an evening or weekend is probably the best time to choose. Next, decide where to have it--in one of your homes, in a church social hall, or in a school. These are some of the possibilities; there are others, depending on your community. Each has advantages and disadvantages.

Invitations should be mailed at least two weeks before the date of the event. If group child care arrangements have been made, be sure to include this information.

Plan your refreshments--keep it simple. Your purpose is to provide a relaxed setting in which people can meet and exchange meaningful information.

Steps for a Party:

1. Meet with 2-3 parents.
2. Decide on:
   a. date
   b. time of day/night
   c. location
3. Make arrangements for meeting site.
4. Mail invitations two weeks ahead.
5. Plan refreshments
6. Prepare name tags.
7. On the day of the party:
   ---- Relax!
   ---- Meet new parents!
   ---- Meet new professionals who can be of help to you and your child.

A film is an excellent way to provide and receive information. It will serve as an excellent catalyst for small group discussions.

Discussion Groups

There are many films available in the area of education for children with special needs. Most of these films may be borrowed for several days at a time; the charges are often minimal. Resources for locating films include local public libraries, school libraries, college and university media centers and the state film libraries in the Departments of Education and Human Resources.

When planning a film viewing session, several points are important:

Time: Getting the film: It is best to request a film or filmstrip two (2) months before the date on which you plan to use it. Good films are in great demand, and waiting lists for borrowing these films are necessary.
Keeping the film: Each film library or owner/producer has a specified time period during which you may keep the film or filmstrip in your possession. This will vary from as little as 48 hours to as much as three weeks.

Money: The making of a film is a very expensive process. Some agencies do not charge for lending a film or filmstrip; many, however, charge a rental fee of $25-$50; others charge a deposit which is refunded when the film or filmstrip is returned in good condition.

Machines: Films are shown on either 16 millimeter or 8 millimeter projectors. The catalog or agency from which you are borrowing the film can give you this information. Some filmstrip projectors have cassette tape players built in, and others do not. If the filmstrip projector does not have a tape player built in, you also need a cassette tape player.

Note: All schools and public libraries own the kind of projectors described in this section. It is very likely that your group can arrange to borrow a projector. A projector screen on which to view the film or filmstrip is desirable. However, the film or filmstrip can be projected on a blank, lightly colored (preferably white) wall. Screens can be borrowed along with projectors.

Discussion: Two or three parents should preview the film. Questions and comments could then be prepared in advance. This would stimulate the discussion by other parents viewing the film for the first time.

Steps for Viewing Films or Filmstrips:

1. Choose a film.
2. Locate the agency for borrowing it.
3. Determine a borrowing date.
   REMEMBER: Allow two (2) months.
4. Arrange to borrow a projector and screen.
5. Find a place to view the film.
6. Mail notices to interested parents, teachers, etc. TWO (2) weeks ahead.
7. Preview film and prepare questions and comments.
8. View the film and discuss.

ORGANIZING AND CONDUCTING FORMAL GROUP ACTIVITIES

A Workshop

The purpose of a workshop can be as far reaching and varied as your creativity and resources allow. A workshop can be as simple to plan as a committee meeting, or it can be as complicated as a Summit Conference.

Let's start at the simple end. Keep in mind that simple does not mean lacking in creativity, time or hard work. For instance:

Several of you have children enrolled in a preschool developmental center. You observe that the infant group has very few materials for use in sensory stimulation. You talk to the preschool developmental center director and ask if you can organize a parent committee to make materials for the class. You and others get together for the purpose of collecting and making items for the class.

Perhaps two or three parents have children who are ready to learn to feed themselves. You obtain the name of a speech therapist, physical therapist, or special teacher. As a group you arrange a time to meet with this person for instruction in feeding techniques.

Monthly discussion groups might be held for the purpose of reviewing films, books, articles, and personal experiences on such topics as discipline, toileting, dressing, independence training. These small discussion sessions can be helpful in discussing ways of coping with the neighbors, grandparents, siblings, or spouse. At times the group may want to restrict the invitations to only parents; at other times the outside counsel and advice of a professional may be desired.

As an example, perhaps your community needs a playground suitable for toddlers. After drawing up plans, contacting the town's planning and governing boards, and obtaining the necessary raw materials, a dozen parents meet at a City Park early Saturday morning for ten hours of hard labor.

You might want to consider a larger full-day, or two-day workshop or conference. There are several advantages to such an event; some of the advantages are: (1) the development of group cohesion as you work toward a common goal; (2) the ability to offer a varied program, in terms of the content and format; (3) the publicity gained; (4) the contacts made. The primary disadvantage is cost, although with careful, prudent planning this can be kept minimal.

The following list can serve as a checklist and guide for planning a day-long conference.

Organize a central planning committee, which should:

1. Choose a conference theme;
2. Choose a date, which is 2-3 months away;
3. Arrange for a place to hold the conference;
4. List topics to be discussed, or presented;
5. Prepare a schedule; remember to include breaks, lunch, a variety of topics, and formats;
6. Arrange for presenters, discussion leaders, etc.;
7. Send out announcements two (2) months in advance;
8. Arrange for publicity (see Primer for Publicity sub-section);
9. Arrange for refreshments;
10. Check the Nitty-Gritty Checklist at the end of this sub-section.

Parent Needs Assessment

As the parent of a handicapped child, you have an excellent idea of the concerns of other parents. You enjoy being involved; you find the efforts you are making rewarding and satisfying.

Each of us enjoys being made a part of the decision. In order to effect the greatest degree of participation you might survey fellow parents to determine their needs through a needs assessment form.

A sample "Needs Assessment Survey" form follows. Add, delete, change it, as needed.

Need Statement	No Need	Some Need	Great Need
1. Information on teaching self-help skills.			
2. Information on infant stimulation.			
3. Help or guidance for siblings of handicapped children.			
4. Information on community resources.			
5. Information on statewide resources.			
6. Finding a babysitter.			
7. Interpretation of evaluation/ diagnostic conference.			
8. Information on toys and games.			
9. Information on language development.			
10. Information on behavior management			
11. Guidance in how to talk to friends and neighbors about my special child.			

Child Care

For any activity involving parents, you may want to consider making group child care arrangements.

To do this you might arrange to use a classroom or two in your church or in your child's school or pre-school. The church or school secretary can readily direct you to the person with whom you can make these arrangements.

Good sources for sitters for such times as this are: Boy or Girl Scouts, high school service clubs, college or university students in psychology, education, nursing, or some other human service field or a teenage Sunday School class. Many such groups are eager for volunteer activities and for the experiences gained from participation.

In order to provide for the happiness of children and sitters, you may want to see that toys, snacks and information concerning the parents' location and time of return are made available.

Providing group child care for a few hours takes very little time to plan and arrange. It can greatly increase the attendance and involvement of parents of special children.

1. Will the room and/or building be unlocked? Obtain the name of person responsible, just in case.
2. Are there plenty of chairs? Can they be arranged as desired?
3. Is there a public address system?
4. Who's responsible for coffee? refreshments?
5. Are there adequate electrical outlets?
6. Is there adequate parking? Are temporary stickers needed?
7. Does the facility conform to the needs of physically handicapped persons?
8. Are media hardware needed (16 mm, 8 mm, slide projectors, screens)?
9. Do you have biographical details on a speaker who must be introduced?
10. Is someone available on the day of the meeting to run errands?
11. Have you planned for a registration desk? Name tags?
12. Are babysitters needed?
13. Is transportation needed?

Nitty-Gritty Questions

ACTIVITIES SUMMARY

TYPE OF ACTIVITY	PURPOSE	ADVANTAGE
Presentation to: Town Board Civic Groups School Board Legislators University professors and students	Provide information; explain needs; seek services; funds.	Contact large numbers of influential people; inexpensive.
Informal get-together: Coffee, pot-luck	Meet other parents; teachers, etc.	Relaxed, informal atmosphere; inexpensive
Discussion Groups: Book/film review Guest speaker Training Session Dialogue	Obtain and exchange information; learn new skills.	Opportunity to find out about things; inexpensive.
Workshops: Make materials Make equipment Discussions	Respond to needs of self and others.	Outlet for providing and obtaining assistance

A necessary element for any successful activity is an organized committee whose members are responsible for specific tasks. The number of tasks and the size of the committee will vary. Whenever appropriate, include members of regional and state staff in the Department of Education, civic organizations, the school system and local colleges or universities on your planning team. These people will provide additional perspectives, but more importantly, they will form a group which can be extremely valuable. Increased community cooperation can provide a broader base of interest in your endeavors.

A PRIMER ON PUBLICITY

Newspapers

There are many ways to publicize a meeting or activity. Some of the possibilities include: newsletters, newspapers, direct mail, radio and television announcements and interviews. The type of publicity you choose will depend on your resources, the type of activity you are planning and your target group. Each type of publicity has an important time and cost factor which must be considered. A brief look at each follows; sample articles, news releases and announcements are included.

Newspaper people are usually very friendly, helpful people. They are eager for stories of local appeal and interest. On the Editorial Page look for the listing of the owner, publisher and editors. Locate the appropriate editor. This might be the Education Editor, City Desk Editor, Feature Editor, Family Editor. The number and variety of editors available will depend on the size of the newspaper. When in doubt, call the City Desk Editor.

A feature story is the best advertising available. When planning a discussion group, film review, speech, conference or workshop, call the newspaper in advance. Invite the Editor to come or to send a reporter to the event. The result will often be a lengthy story, accompanied by pictures. This, of course, will create considerable attention for your parent group and its effort and activities!

How to obtain Newspaper Coverage - A Summary:

1. Call the Editor.
2. Introduce yourself and your organization or purpose.
3. Ask the Editor when you might obtain coverage.
4. Send a news story release (a sample follows).

Sample
News Release

Include the name, the name of the parent group, a telephone number and address.

For release on Sunday, May 9, 1980:

On Tuesday evening, May 11, Parents of Children With Special Needs will meet at the home of Mr. and Mrs. Jack Jones. The group will view the film "Lisa's World". Dr. Jack Rogers will lead the discussion following the film.

The Parents of Children With Special Needs is an organization which was formed for the purpose of obtaining and providing information and services to handicapped children and their families.

The Parents of Children With Special Needs will be holding a three-county workshop in June. This will focus on providing local educational services during the coming school year. For further information, contact Jane Smith, 387-1234.

Your local television station may have a local talk show. Check your TV listings for such a show and note the time of day; it will likely be a daytime show. Watch the show and find the name of the producer. This will usually appear on the screen at the end of the show. Producers of local "talk shows" are very eager for material of interest. As the parent of a child with special needs, you have a high interest story. The result could be extremely advantageous.

How to Obtain Television Coverage A Summary:

1. Call the producer.

2. Introduce yourself and your organization or purpose.

3. Ask if you might appear on the show for an interview.

4. Send a written statement describing your group and its goals.

Television stations must make a certain number of free public service announcements. Call the television receptionist and ask for the person in charge of public service announcements. Utilize this service for publicizing meetings, workshops and conferences.

*NOTE: TV announcements are improved if they are accompanied by a visual image. Providing the TV station with a written announcement as well as an appropriate slide, poster or a few seconds of a videotape will increase the impact of your announcement.

Radio

Radio stations also conduct talk shows or interviews of local interest. Contact the station and ask to be connected with the person in charge of the local interview program.

How to Obtain Radio Coverage A Summary:

1. Call the station.

2. Introduce yourself and your organization or purpose.

3. Ask if you might appear on the show for an interview.

4. Send a written statement describing your group and its goals.

Radio stations must make a certain number of free public service announcements also. Call the radio station receptionist and ask for the person in charge of public service announcements. Utilize this service for publicizing meetings, workshops and conferences.

Sample Radio or Television Announcement:

15 seconds:

A one-day conference on problems faced by parents of handicapped children will be held at the Mt. Moore Presbyterian Church on October 9. All interested parents and professionals are urged to attend. For further information call Jane Jones, 867-1234.

Submitting articles and announcements to the newsletters of other organizations is usually a very inexpensive method of transmitting a message and receiving advertisement. You should contact the group's newsletter chairperson and find answers to the following questions:

1. What is the deadline for submitting articles or announcements?
2. What is the maximum length of an article accepted by their newsletter?
3. What is the acceptable size of an announcement?
4. Should the material submitted be typed?

Developing your own newsletter can be very worthwhile. You can determine the answers to the above questions. In addition, your newsletter is mailed exactly to those persons to whom you wished it mailed.

Developing your own newsletter is expensive, however. The newsletter must be:

1. Written
2. Typed
3. Duplicated or printed
4. Addressed
5. Mailed*

*If your parent group does not have a bulk rate permit, contact the Post Office about receiving one. The initial expense is high; however, considering the cost of first-class postage you will soon recover the cost!

IMPORTANT!!! Publicity applies not only to initial notices about meetings but to follow-up notices AND to coverage during the meeting. The media are eager for local interest stories! Given adequate notice they are most likely to cooperate.

Newsletters

ADVISORY GROUPS

State Advisory Panel For Exceptional Children

The establishment of the Kentucky State Advisory Panel for Exceptional Children is a requirement of P.L. 94-142. Membership on the panel includes representation of handicapped individuals, teachers of exceptional children, parents of exceptional children, state and local education officials, special education program administrators, and representatives from other state and local (public and private) agencies/ groups who have an interest in programs for exceptional children. Panel members are appointed by the Governor for three year terms. The activities of the panel are paid for through funding which Kentucky receives under P.L. 94-142. These funds are also used to reimburse expenses incurred by panel members who are not state employees.

The panel meets quarterly. These meetings are normally scheduled for the fourth Thursday and Friday of January, April, July and October, although schedule conflicts sometimes necessitate moving this meeting date up or back a week. Panel meetings are held in the Capital Plaza Tower in Frankfort and are open to the public. Information regarding panel meetings is disseminated through the Department of Public Information in local newspapers throughout the state and in the Department of Education publications, EDNews and Leaders Lines.

Activities of the panel include advising the Department of Education of unmet needs and funding within the state in the area of education for exceptional children, commenting publicly on the state's Annual Program Plan and proposed Kentucky Administrative Regulations and Standards, and assisting the state in developing and reporting information and other evaluation reports required by the U.S. Office of Education. The panel also reviews written findings of fact and decisions resulting from impartial due process hearings. It summarizes these activities in an annual report which is submitted to the Department of Public Information and which is made available to the public.

For further information concerning the panel, contact:

Bureau of Education for Exceptional Children
Division of Supporting Services
Capital Plaza Tower, Room 806
Frankfort, Kentucky 40601
(502) 564-3790

Developmental Disabilities State Planning Council

The council sees its role as a balance between the advocates for developmentally disabled persons, and a barrier to programs which should not be funded. The goal is to achieve a sound, rational program for Developmentally Disabled persons.

At the present time the State Planning Council is attached to the Institute for Children which is an advisory council to the Secretary of the Department for Human Resources. The composition of the council is six members with two members representing state agencies, two representing non-governmental agencies or providers, and two who are consumers. The overall function of the State Planning Council is to set the pace for the direction and advocate for the development and growth of services to the developmentally disabled population of Kentucky. To accomplish this overall function, the State Planning Council has concentrated its efforts toward planning for services to developmentally disabled persons.

The main function of the council is to set the pace for direction, development, and growth of services to developmentally disabled persons through its responsibilities and membership.

Other functions of the Council which have been identified by the Developmental Disabilities Services Act (DDSA) regulations and the executives establishing the Council are as follows:

1. Supervise the development of the State Plan by providing guidance through: the establishment of goals and objectives; identification of gaps in services; setting priorities for the allocation of funds.

2. Monitor and evaluate the State Plan to insure that established goals and objectives are being achieved.

3. Increasingly serve as an advocate for persons with developmental disabilities.

4. Foster cooperation and communication among state, county, municipal, voluntary and private agencies providing services to developmentally disabled persons to assure that such services are delivered effectively and without duplication.

5. Review and comment on, to the maximum extent possible and feasible, all State Plans in the Commonwealth which relate to programs affecting persons with developmental disabilities.

6. Promote public awareness of the needs and problems of developmentally disabled persons and their related budgetary implications.

7. Review and comment upon laws and practices relating to developmentally disabled persons.

8. Encourage the development of training and other related programs to more effectively prepare professionals to work with developmentally disabled persons in conjunction with the University Affiliated Facility at the University of Kentucky and other colleges and universities.

9. Encourage the development of training and recruitment programs to promote and develop employment of developmentally disabled persons.

10. Encourage and support pertinent research efforts, and stimulate planning at the community level.

For additional information contact Department of Human Resources, Bureau for Health Services, 275 E. Main Street, Frankfort, Kentucky 40601. Phone: (502) 564-4504.

Committee For A Comprehensive System of Personnel Development

In order to carry out the requirements of federal legislation and regulations pertaining to personnel development under P.L. 94-142, the Kentucky Department of Education has established the Committee for the Comprehensive System of Personnel Development (CCSPD).

The major purposes of CCSPD are to advise and assist in the development of policies and procedures which will assure that a sufficient number of qualified personnel are available to provide a free, appropriate public education to handicapped children in the state.

CCSPD consists of a committee-at-large which meets approximately four times a year; membership of the committee-at-large is comprised of thirty-four (maximum of forty) representatives of such agencies as the Department for Human Resources, parents of exceptional children, advocacy groups, Council on Higher Education, colleges and universities, the Bureau of Vocational Education, the Bureau of Instruction, and local school districts, including administrators, regular educators and related services and support personnel.

Five task forces which have been established to carry out functions of the CCSPD related to major topical areas are as follows:

Task Force on Needs Assessment

Task Force on Personnel Standards

Task Force on Training Delivery Systems/Resources

Task Force on Interagency Communication

Task Force on Legislation

The primary purposes of the task force are: (1) to review current practices related to each task force area; (2) to review problem areas and model systems/procedures; and (3) to make recommendations for needed changes in each of the five areas. Each task force provides information and recommendations to the steering committee which is responsible for incorporating this input into unified personnel development plan.

The membership of the task forces will include both members of the committee-at-large and other representatives of involved agencies/organizations according to the needs related to carrying out the responsibilities of each task force by contacting the Bureau of Education for Exceptional Children or a committee member.

For additional information contact the Bureau of Education for Exceptional Children, Capital Plaza Tower, Frankfort, Kentucky 40601. Phone: 502/564-2067.